Please Be Normal!” My Experience Working for NAMI

By

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The numerous articles about NAMI (the National Alliance on Mental Illness) on Mad in America over the years have always piqued my interest because they were so closely relatable to what actually happens at a NAMI office. In my experience, NAMI deserves all the criticism it gets, if not more.

I was employed as a mental health “advocate” for a NAMI affiliate for almost four years and volunteered for three years before that, so I saw how NAMI works for a good seven years. I got involved with the organization for the same reason many other naïve people do: trying to help people with “mental illness.” As someone with a family member diagnosed with a “mental health condition” and having “lived experience” myself, it seemed like a logical fit at the time. I had all the NAMI bases covered: I’d done the NAMI Walks, attended the support groups, and had also worked in the mental health system. I vividly remember going to my first family-support group, which was largely made up of older parents complaining about their adult children’s mental illness. I didn’t think about it much at the time and figured they were just blowing off steam, but I was wrong.

It wasn’t until I began working for NAMI full time that I saw what it was really all about. Up to that point, I had been working for an affiliate of Mental Health America as an “advocate.” It was a job that, at first, I was really excited about. I thought I could change the mental health system from the inside and get rid of all the things that I thought were wrong, such as forced treatment, the overuse of psych meds, lack of housing, and so on. (Did I mention I was naïve?) The MHA affiliate was closed for financial reasons and NAMI got their contract. I was aware that NAMI, as a national organization, was taking money from drug companies and insurance companies and supporting “assisted outpatient treatment.” But I thought an affiliate might be different. Nope.

One of the first things I remember when I first started at NAMI was how much they seemed not to like outsiders. I did come from a rival organization, if you could call it that, but already knew some of the people who worked there and had already been doing the job for a few months. Yet it seemed like the air would be sucked out of me each time I would walk into the office. As if people were talking about me behind my

back. I thought I was just new. Wrong again.

As an advocate, my job was to make sure that my “clients” had a voice and a choice in their treatment and that their rights were being upheld by the system. Many clients had been involuntarily committed/forced drugged. I became increasingly frustrated with this situation and felt helpless that I couldn’t do more about it. So I asked the CEO, who was my boss at the time, what some solutions might be.

I said, “I feel that a lot of my clients’ rights are being violated. What can I do? This isn’t right.”

The reply: “They don’t have rights.”

I was shocked and saddened. I was beginning to realize that a lot of people at NAMI—not everyone, but many—looked at people with “mental illness” as non-people, non-human, the “other.” Day after day, I took phone calls from family members calling their children or loved ones “crazy,” telling me that their family member “needs to be locked up,” that “we need more state hospitals” and “more involuntary commitments.”

Inside the office, it was no different. Staff who had mentally ill (their words) family members spent their entire lunches talking about how bad mental illness was and how much it ruined not their family member’s lives, but their own. About how inconvenienced they were, about how it seemed as if their loved one were dead. What they were implying, but didn’t come right out and say, was “WHY CAN’T THEY BE NORMAL LIKE ME?” If NAMI had a tagline, it would be “Please be normal like us.” Having someone with a mental illness in your family at NAMI made you part of some cult-like club. As someone who has a parent with a mental health condition, I was expected to share details about his life. I needed to become part of the “Lunchtime Gossip About Our Family Members Club.” It started to creep me out.

Over time, I became more and more disillusioned with my job, the system, and especially working for NAMI. My own mental health started to suffer. I was constantly depressed and would dissociate in my office. It was obvious to everyone that I disliked it there. Every day I would drag myself home. I can’t speak about other NAMI affiliates, and I’m sure some fine people work at them, but I know that the NAMI I worked for targeted dissenters and people they just didn’t like. They wouldn’t fire you, but would make you so miserable you would quit. I saw a trend of people quitting on poor terms after being targeted in this way, driven out by gossip and passive-aggressive bullying. I know they hired individuals based on their being a person of color for the sake of “diversity,” only to let them go/make them quit in short order because they didn’t

meet the “NAMI standard.” After I saw friends pushed out for no real reason besides standing up for what they believed in, I knew the leadership would come for me sooner or later. And they did.

I got my first performance review in more than two years, which was basically a personal attack. A board member had heard and complained about a podcast on which I had been a guest. Or so I was told by the CEO. In the podcast (which I did on non-work time, and never mentioned NAMI by name) I had criticized forced treatment and family-member discrimination. Because of this, I was accused of being “anti-family,” whatever that meant. I had a family member with a mental illness, so the accusation made no sense. I now think what it was really about was the guilt. I heard that guilt on the phone with people every day, guilt about how they treated their family member with a mental illness. The othering. They knew it, deep down.

I pushed back that my podcast had nothing to do with NAMI and that I had never mentioned who I worked for. It didn’t matter. I was told I lacked insight into the things I said. It sounded very familiar to the way NAMI talks about “people with mental illness” and anosognosia. I was told this is a “family organization” and that “we support families.” The lines were drawn. My punishment: I had to attend up to eight months’ worth of classes on how to be a “good family member.”

I was done. I felt helpless, so I quit. I refused to be censored or be trapped in the NAMI cult anymore. In telling this story, I’m not looking for sympathy from anyone. I’m glad I left. My livelihood was screwed around with for childish reasons. It was frustrating. However, had I not worked in the mental health system and at NAMI, I don’t think I would have become so critical of forced treatment or looked into alternatives to the traditional mental health system. I don’t think I would have logged on to Mad in America or Mind Freedom International, whose members people at NAMI mocked for being “radicals.” I don’t think I would have formed a point of view.

I’m glad I no longer work in the mental health system. I’m glad I don’t have to hold my opinions back or be looked at like I’m “crazy” because I think psych meds can be harmful. NAMI is not about changing things; it is about branding and getting money from insurance companies and making nice NAMI Walk t-shirts. It was never about any substance. And it was certainly never about addressing the abuses in the system. The existing mental health system—at least the very narrow one that NAMI promotes—offers nothing to me nor to so many other people seeking support.